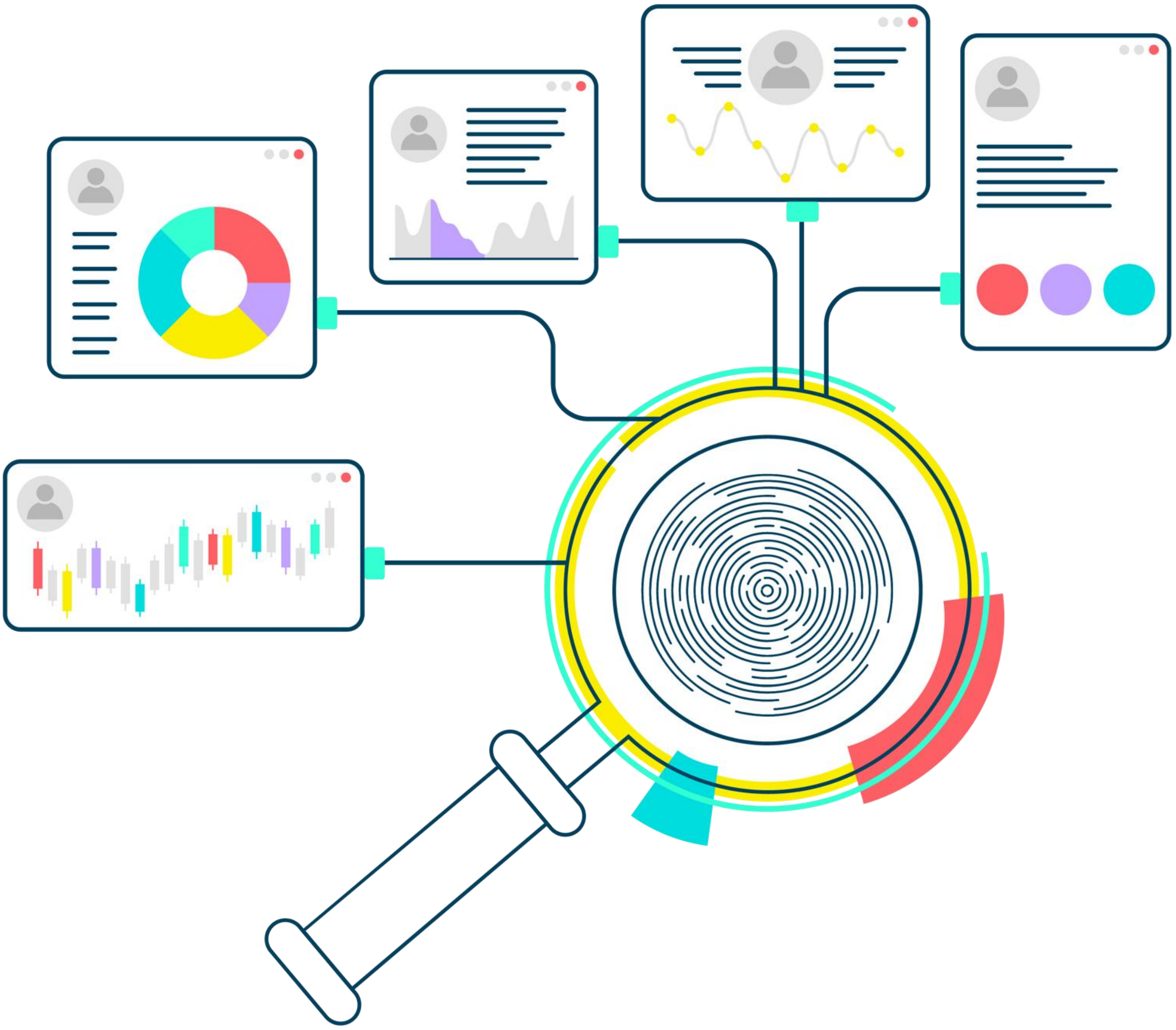
Understanding Patient Data



EHDS Unpacked

Global health data hackathon

Contents

Executive Summary

In late May, Understanding Patient Data, with Prof. Dr. Henrique Martins and funding from Wellcome, convened a Global Health Data Hackathon bringing together colleagues from non-EU countries (referred to in this report as "third countries" in line with the European Health Data Space (EHDS) Regulation). The aim was to use the EHDS as a starting point for a wider international conversation exploring how countries can work together so that health data is used safely, fairly, and effectively to improve care, support research, and deliver public benefit.

Participants explored four connected domains where progress is needed:

- Policy and governance;
- Individual care and research use;
- Technical infrastructure;
- And public awareness and education.

Across these discussions, a clear shared objective emerged- to move beyond high-level agreement and identify practical steps that can help countries build trustworthy, interoperable, and publicly accountable health data systems. Five key findings stood out:

- **Shared rules need shared responsibility.** Laws, standards and safeguards are important, but they need to be supported by clear leadership, participatory governance and practical accountability.
- **Countries need a common direction.** A shared vision, potentially expressed through a Global Health Data Space could help align national efforts while recognising different legal, cultural and technical contexts.
- **Data access must be simpler, safer and more visibly beneficial.** Clearer access routes, stronger safeguards and better feedback to patients and communities are needed to show public value and sustain trust.
- **Interoperability depends on implementation capacity.** Standards and infrastructure matter, but so do workforce, procurement, operational change, funding and long-term investment.
- **Trust must be designed into the system.** Transparency, public engagement, patient involvement, cultural sensitivity and evidence of public benefit need to be built in from the start.

The hackathon also created a collaborative space for participants to compare national experiences, identify shared priorities, and test where international cooperation could add most value. Participants recognised that progress would require both practical near-term steps and longer-term mechanisms for continued collaboration.

Overall, the discussions showed strong appetite for a more connected global approach to health data. The immediate opportunity is to turn shared ambition into practical collaboration: clearer governance, better technical alignment, stronger public engagement, and concrete pilots that demonstrate value for patients, health systems, and research.

Henrique & Lucy

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Policy and governance

Overview

Legislation provides an important starting point for effective health data systems, but it is active, participatory governance and clear governmental leadership that are critical to driving meaningful progress. Participants highlighted the need to create intermediary "agency" spaces between high-level strategic and policy forums (such as the World Health Assembly and the Global Digital Health Partnership) and national-level implementation. These spaces could enable practical, cross-country data exploration and sharing initiatives. Additionally, adopting a shared vision – such as realised Digital Health Diplomacy leading to a Global Health Record – was seen as a useful foundation for shaping policy dialogue and strengthening international cooperation and diplomacy.

Digital Health Diplomacy *refers to the concentrated international efforts towards supranational interoperability in eHealth/Digital Health. These may include international agreements for mutual health data transmission, recognition of information systems or common approaches to the use of international standards.*

The domain

This domain covered the policies, documents and practical approaches that shape how health data is used. It also covered governance arrangements, including laws, regulations, organisational responsibilities, safeguards, inclusion and ethics. Participants used the EHDS as a shared reference point. This helped them compare national approaches and discuss how laws can enable or limit cross-border data sharing, where inappropriate data access might arise, and how consent models work in practice.

There was limited reference to frameworks such as the International Patient Summary (IPS) and the Global Digital Health Partnership (GDHP). Participants also noted that the WHO 2025 strategy is too high-level to guide implementation. Together, this points to a gap between global strategy and practical action. It also shows the need for stronger policy coordination and digital health diplomacy.

A further consideration is the need for explicit governance of public benefit, including clearer criteria for when data access is justified, how benefits are returned to patients and health systems, and how communities can challenge or influence decisions. Without this, trust risks being treated as an outcome of compliance rather than as an ongoing governance responsibility.

Challenges

Participants identified several connected policy and governance challenges. A central issue is the gap between ambitious policy goals and the practical ability to implement them consistently. Countries also need to align different legal, ethical and governance frameworks so that data can be used safely across borders. Many countries still need to address challenges within their own systems before, or alongside, work on international data sharing.

Questions of accountability – particularly regarding AI – remain unresolved, alongside concerns about how to balance power among data custodians, individuals, and the broader public interest.

Participants also highlighted ongoing barriers to data access for patients, professionals and researchers, emphasising the need for clearer, more streamlined and transparent processes. They also noted that fragmented authorisation processes and weak incentives for data holders make it harder to build a sustainable culture of data sharing that delivers wider public benefit.

Finally, achieving policy level interoperability across varying levels of digital maturity, standards adoption, and infrastructure development continues to pose a significant challenge.

Solutions

Participants agreed that these policy and governance challenges require coordinated action at several levels. Global strategies need to be translated into practical steps that work in national contexts. Participants saw value in using regional political forums, such as ASEAN, APEC and the Gulf Cooperation Council, alongside international bodies such as the United Nations and the World Health Organization. They also highlighted the role of digital health collaborations, including the Global Digital Health Partnership (GDHP), and standards bodies such as the Joint Initiative Council and wider harmonisation efforts.

However, these mechanisms will not be enough on their own. Progress will also require practical legal alignment, including GDPR-like frameworks in regions such as the African Union. Smaller sub-regional groupings also show potential to contribute to this initiative, especially where countries share history, geography or health system features. One example is collaboration between Australia, New Zealand and Pacific Island countries on telehealth.

Closing the implementation gap will also require focused coalitions between countries. These coalitions should be able to deliver practical results, for example through smaller, high-impact projects similar to EU "interreg" projects. Working to shared principles or minimum standards could help show quick wins and build momentum. At the same time, harmonisation must start by recognising local differences. Countries need to understand how legal, ethical and governance frameworks have developed in different settings. Finding common ground can support alignment, especially through work between national ethics bodies and international academic institutions. AI tools may also help compare laws and overcome language barriers, whilst universities can support this need by developing joint research and policy proposals.

Case vignette: The United States framework for accountable health systems

The US approach to health data centres on **policy-led governance and transparency**. The **NIST AI Risk Management Framework** provides widely adopted guidance for managing risks in AI and data systems, emphasising accountability, oversight, and trust. The **CDC Public Health Data Strategy** strengthens governance through data standards, stewardship, and system-wide coordination.

Public engagement is supported through open data and transparency, particularly via HealthData.gov, which enables public access, scrutiny, and reuse of datasets. Together, these mechanisms demonstrate a **governance model that builds trust through clear standards, oversight, and public visibility**.

Strengthening accountability, especially for AI and cross-border data use, will require both legislation and stronger certification and health technology assessment frameworks. Participants highlighted the need to move towards mutual recognition agreements. These are still largely absent for AI tools and remain limited for medicines and medical devices. Better coordination between regulators, such as the Food and Drug Administration (FDA), European Medicines Agency (EMA) and counterparts in Korea, Japan, Australia, Canada, Brazil and India, could support more consistent evaluation before and after products enter the market. Cross-border telehealth also raises accountability questions. These could benefit from shared global principles or step-by-step treaty-based approaches, whilst broader alignment would also support industry, including work such as the University of Oslo's electronic product information initiative.

To reduce barriers to data access, participants pointed to governance models similar to the EHDS Health Data Access Bodies. These measures could help establish clearer and more transparent processes, supported by government-led monitoring mechanisms and measurable indicators to strengthen accountability. Extending such a framework to third countries could enable a 'one-stop shop' for data access, allowing researchers to more easily find, request and retrieve comparable datasets across jurisdictions.

Finally, countries vary significantly in their levels of policy interoperability and digital maturity. Addressing these disparities will require learning from more advanced systems while ensuring global progress remains inclusive and scalable. Economic and social factors are equally important – sustainable data sharing depends on clear funding models and well-designed incentives for all stakeholders. Frameworks that recognise and reward contributions to data sharing can further strengthen participation and build trust.

Individual care and research use

Overview

For the most part, interoperability remains the primary barrier to the effective use of health data in care settings, particularly in achieving integrated systems, while researchers globally continue to face challenges related to slow time-to-data access. Addressing this requires both regulatory and financial measures, including mandating interoperability and aligning incentives to promote the adoption of compatible digital health solutions. There is also a pressing need for stronger coordination between policymakers and standards development organisations, as well as among these bodies themselves. Participants emphasised that joint governmental and non-governmental forums must move beyond high-level rhetoric and towards concrete, implementable decisions and tangible legislation that can support the acceleration of research and the subsequent care impact.

The domain

This domain covered the use of personal health data for care and research. This includes integrated care, cross-border care, telehealth, academic research, commercial research and policy research. It also focused on the link between primary and secondary uses of data. Used well, this cycle can improve care, prevention and health outcomes, including through AI and evidence-based insights. Discussions also covered consent, the role of patients, and how to balance secondary data use with public trust.

Challenges

Participants identified several challenges in using health data well for care and research. Clinical data needs to be higher quality, more consistent and easier to use. This is essential for meaningful research. At the same time, access to data must be balanced with good governance, security and trust. Participants also emphasised the need to strengthen skills, capacity and incentives among clinicians and researchers, alongside fostering closer collaboration across organisations and countries. Improved integration between care and research would further support the development of learning health systems.

A persistent challenge is that the anticipated public benefits of health data reuse are often long-term, indirect, and difficult to make tangible, making the overall public interest hard to define and measure. Compounding this, patients and communities do not always see a clear line of sight between their data contributions and resulting improvements in care, prevention, or research. Making this feedback loop more visible will be essential to sustaining participation and avoiding perceptions that secondary data use is too remote from meaningful patient benefit.

Solutions

Addressing these challenges will require coordinated action on data quality, resources, skills and collaboration, with a key priority being improving the quality, consistency and usability of clinical data. Participants highlighted the value of a structured MEELS approach: mandating, educating, evaluating and labelling, and supporting the use of international standards such as ICD, SNOMED, and LOINC at the point of care, recognising that high-quality data collection during care is essential for later research and AI use. This should be supported by strong metadata catalogues, as promoted under the EHDS, and data quality labelling initiatives such as the EU-funded QUANTUM project. Some returns from research and secondary use should also be reinvested in improving data quality.

Balancing data access with governance, security and trust requires both clear evidence of the benefits of data sharing and robust mechanisms to manage risk. Approaches such as open datasets and the principle of “collect once, use many times” can improve efficiency, protect privacy and demonstrate tangible public value. At the same time, clinicians, researchers and institutions need better tools and training to make effective use of data. Metadata catalogues, for example, should be accessible and meaningful to non-technical audiences. Education initiatives, such as the XiA Project, alongside global learning networks, can play an important role in building these capabilities.

Strong feedback loops between researchers, data custodians and frontline health professionals are also essential. These connections can improve the quality of data capture and enable a fairer distribution of the value generated from data use. Moreover, establishing clear criteria for what constitutes public interest can help balance public and commercial priorities, supporting more transparent and trustworthy data sharing.

Case vignette: How Japan enables secondary use of health data

Japan's **Next Generation Medical Infrastructure Act (2018)** enables the secondary use of health data from secondary care (e.g. hospital records, diagnostics, treatment pathways) for research and innovation, while maintaining privacy safeguards. Under this framework, hospitals share data with **government-certified intermediaries**, which securely process it into anonymised or pseudonymised formats before release to approved users.

Public engagement is built into the model through **transparency requirements and opt-out mechanisms**, helping maintain trust. Patients are informed that their data may be used for research and have opportunities to decline, supporting social licence for data use beyond direct care.

For secondary care, this approach enables **large-scale analysis of real-world clinical data** to improve treatment pathways, service planning, and innovation without repeated consent requests.

Collaboration can be further strengthened through practical mechanisms. These include sharing registries and good practice, using common data models such as OMOP-CDM through OHDSI, and encouraging bilateral exchanges and institutional partnerships. International medical societies, such as ESMO and the International Diabetes Federation, can also support cross-border knowledge sharing. This is especially valuable when they work with researchers and digital health stakeholders.

Finally, learning health systems depend on showing real-world impact. Evidence needs to go beyond technical implementation, to show how data use improves health outcomes and supports policy decisions. Benchmarking and cross-country comparisons can provide valuable insights, particularly where open data and strong political support are in place. Aligning standards across the entire data lifecycle – from initial capture through to research – will be essential to enable meaningful comparison and collaboration. Harmonised metadata registries can further support this effort, helping to lay the groundwork for interoperable data systems that can operate effectively across countries.

Technical infrastructure

Overview
National health data infrastructures remain highly heterogeneous, underscoring the need for sustained investment to support their development and scalability. The use of common standards was identified as essential to achieving economies of scale and scope. Participants recommended initiating small-scale, cross-country data-sharing pilots and collaborative data exploration exercises as practical steps toward building a future global infrastructure composed of modular components that meet countries' current needs, such as Secure Processing Environments (SPEs) or Health Information Exchange (HIE) systems. The creation of a global registry of successful case studies was also proposed, both to demonstrate real-world impact and to encourage a culture of benchmarking and cooperative competition that can drive progress and innovation.

This domain

Technical infrastructure and public awareness were explored through questions about interoperability gaps, data silos and barriers to scaling. In many participating countries, the technology itself is relatively mature, however, implementation is often limited by basic IT capacity and, more importantly, by low trust at national and global levels. This showed the close link between infrastructure and trust.

Infrastructure was understood broadly – it includes hardware and software, but also workflows, user engagement, integration, data governance and secure, person-centred systems, including Secure Processing Environments or Trusted Research Environments for secondary use of health data.

Challenges

On the first day of the hackathon, participants identified several connected challenges in building effective and scalable technical infrastructure for health data. A central concern was how to achieve true interoperability across fragmented systems, data silos and proprietary vendor

environments. Participants also discussed how to exchange data efficiently at scale. This is closely linked to the challenge of developing and using common international standards, such as HL7, FHIR and SNOMED, in ways that are affordable, widely adopted by industry and adaptable to local contexts.

Participants also noted ongoing infrastructure fragmentation. This includes the lack of common identifiers, inconsistent data architectures and isolated systems. These issues limit secure data sharing across borders and within individual countries.

Another key challenge is balancing national priorities with international collaboration. National priorities include data sovereignty, regulation, compute capacity and funding. In many African health systems, AI tools may exist, but countries often lack the compute capacity to run, test or adapt them locally. Without regional public interest compute, ministries cannot test models independently, adapt them to local languages or workflows, or keep national health data under domestic jurisdiction. This makes compute capacity essential for sovereignty, safety and sustainable AI adoption. Participants also stressed the need for aligned incentives, leadership and long-term investment across governments, vendors and organisations.

Also emphasised was the importance of implementation capacity, as even where standards and platforms exist, health systems often lack the workforce, procurement capability, and operational change management needed to embed them reliably. Technical infrastructure should therefore be understood as an operating model as much as a technology stack.

Solutions

Addressing these infrastructure challenges requires a coordinated, standards-based approach. This should tackle interoperability, fragmentation and sustainability together. Participants again highlighted the value of a MEELS approach, applied to open and interoperable systems. This includes open architectures and specifications, such as application programming interface (API)-based systems, HL7 FHIR, and SATRE-inspired Secure Processing Environments or Trusted Research Environments. It also includes open data models such as OMOP and OpenEHR, and open or fairly licensed terminologies such as LOINC. Systems should align with FAIR principles and formats such as the European EHR Exchange Format. Preventing vendor lock-in is critical to ensuring sustainable and equitable health systems – this requires actively discouraging reliance on proprietary platforms and increasing awareness of donor-funded electronic health record systems that may lead to long-term data dependency or enable inequitable data extraction. At the same time, core IT infrastructure – including hardware, connectivity, and ongoing maintenance – should be recognised and funded as essential components of public health infrastructure, rather than optional add-ons.

Industry engagement is also important, including digital health companies and telecommunications providers. Governments can support adoption by building standards into publicly funded projects. They can also use platforms such as the Global Digital Health Partnership to share emerging needs, including telemonitoring, AI applications and metadata systems. These needs should then feed into standards development through established coordination routes. It should also be recognised that interoperability goes beyond technical data exchange, as it equally depends on shared definitions across health systems, as well as agreed standards for secure data environments – such as SPEs – to enable federated analytics at a global scale.

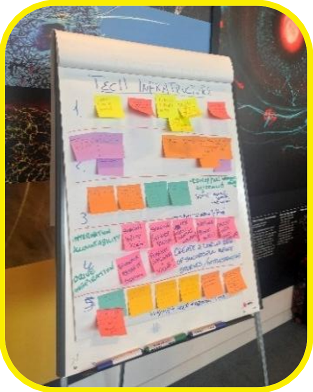
Case vignette: Switzerland's trusted health data framework

Switzerland's Swiss Personalized Health Network (SPHN) prioritises the development of a robust, interoperable **national data infrastructure** to enable data-driven and personalised health research. Central to this are the **National Data Streams**, which standardise data formats, enable secure linkage across institutions, and support federated access to health data. This infrastructure ensures high data quality, interoperability, and controlled, scalable access for research, forming a **reliable backbone** for the secondary use of health data.

Public and patient involvement and engagement (PPIE) is integrated into infrastructure design through **multidisciplinary consortia** including patient representatives. Their input has directly informed governance frameworks, access procedures, and transparency measures, ensuring technical systems reflect societal values.

By aligning advanced data infrastructure with ongoing public engagement, Switzerland strengthens trust and legitimacy in how health data is shared and reused.

To reduce fragmentation and support cross-border data sharing, countries need shared approaches to metadata, cybersecurity, data protection impact assessments and ethical review. A single global electronic identification system may not be realistic. However, interoperable eID frameworks, such as the EU's eIDAS model, can support recognition across jurisdictions while preserving national sovereignty. Countries can also balance national priorities with global collaboration by focusing on economic benefits, shared infrastructure and benchmarking. A global registry of success stories could help show value and encourage others to adopt similar approaches.



Finally, long-term sustainability will depend on recognising the value of health data and reinvesting some of that value into infrastructure. This could include capturing value created by industry, such as pharmaceutical or digital health companies, and reinvesting it in the technical and social foundations of data sharing. Stronger public-private partnership frameworks could create clearer incentives and pathways for sustainable data sharing. Together, these measures can support a more interoperable, equitable and resilient global health data ecosystem.

Public awareness

Overview

Public audiences are even more diverse globally than healthcare systems themselves, making engagement particularly complex. Participants stressed that trust in health data systems is closely linked to education and involvement, and that raising awareness alone is insufficient without deeper efforts to build understanding and confidence. To address this, the creation of a global network of patient and patient data associations was proposed, operating under neutral, non-governmental or multilateral structures such as standards development organisations or philanthropic bodies. Supporting and connecting health data activism movements and patient advocacy initiatives across different national contexts was also identified as a key opportunity to strengthen public engagement and foster trust worldwide.

This domain

Public awareness and education were explored broadly. This encompassed digital health literacy and the public's ability to understand how both individual and collective data are used. These uses range from personal benefits, such as care, prevention and emergency response, and wider public benefits, such as research, innovation and health data economics. The domain also covered the public's ability to act on this understanding, including through feedback, engagement and digital health rights such as accessing, correcting or sharing personal data. Drawing on UPD's recent work, participants discussed the importance of evidence-based communication, media engagement and patient-centred stories. They also recognised that awareness, trust and patient involvement vary widely across countries.

Challenges

Participants agreed that improving public awareness of how health data is used is a significant challenge. A key concern is how to build and sustain public trust, particularly in the context of worries about privacy, potential misuse, and scepticism toward governments or institutions. Clear, transparent communication was noted as essential, ensuring that both individual benefits and wider societal value are explained in an accessible and compelling way.

Public understanding of health data, AI, and data sharing varies widely, meaning communication must be tailored to accommodate different levels of knowledge, experience, and access. Participants also emphasised the importance of meaningful public engagement in decision-making processes, underpinned by inclusive and accessible communication that enables informed participation. At the same time, messaging needs to be carefully framed – sensitive to diverse cultural contexts and mindful of the risk of inadvertently triggering mistrust or backlash.

There is a further need to address misinformation and low-trust information environments directly. Public awareness strategies should anticipate contested narratives about data use and equip trusted messengers with clear, evidence-based explanations before concerns become entrenched.

Solutions

Building public awareness and trust requires a balanced, transparent and culturally sensitive approach. It needs communication, education, governance and ongoing engagement. Participants recognised that breaches or risks can never be removed completely, yet trust can be strengthened if systems can show that they are doing everything reasonable to protect data, and demonstrate sustained investment in privacy-preserving technologies. Within this, systems must strike a careful balance, avoiding being so restrictive that data cannot be effectively used, or becoming too open and insufficiently protected. These trade-offs need to be communicated clearly to both professionals and the public. In addition, different types of health data may require tailored safeguards, reflecting varying levels of sensitivity and risk.

A further key priority is to communicate not only the risks but also the benefits of health data use. Current messaging often places strong emphasis on rights and protections but does not consistently articulate the tangible personal and societal value that data can deliver. Participants highlighted the need for further research into which communication approaches are most effective in building or restoring trust, as the evidence base remains limited. Early indications suggest that approaches such as patient stories, real-world outcomes, and examples of cross-border research can be impactful. However, these strategies require more systematic testing to understand how and when they work best.

Healthcare settings were also recognised as important spaces for communication and engagement. Health professionals are often among the most trusted sources of information, but they require appropriate training and support to fulfil this role effectively. Joint education for healthcare staff and communication professionals could help improve the quality, clarity, and consistency of messaging.

Participants also highlighted the value of co-creating materials with patients and communities, ensuring that communication is more relevant, accessible, and credible. At a governance level, mechanisms such as citizen panels and patient advisory groups can provide meaningful opportunities for public involvement in decision-making, particularly for marginalised communities who may experience health data collection and use differently. Examples from countries such as Australia and Canada demonstrate the advantages of having formal public advisory group.

Case vignette: Australia's Indigenous Data Commons

Australia's ARDC HASS and Indigenous Research Data Commons embeds Aboriginal and Torres Strait Islander leadership into national data infrastructure, ensuring data is governed by community custodians through a **federated model grounded in trust and transparency**.

In this co-produced initiative, **Aboriginal and Torres Strait Islander communities act as equal partners** – defining problems, setting priorities, and shaping governance – through sustained partnerships and ongoing collaboration. They directly influence how data is collected, described, accessed, and used, with tools and standards tailored to reflect Indigenous knowledge systems and cultural protocols.

This tailored, community-led approach builds trust, ensures **cultural safety**, and delivers research that **reflects local values and priorities**.

It was also recognised that different groups engage with different platforms, and subsequently respond to varying types of messaging. Communication should therefore be tailored to specific audiences and cultural contexts, using channels and formats that align with how particular groups prefer to receive information. Targeted use of social media and digital platforms can be especially effective when designed with these preferences in mind. This approach reflects moving beyond simply informing people to more participatory models – informing, involving, consulting, collaborating, co-producing, and ultimately empowering individuals and communities.

Finally, international efforts on incentives and ethics must be both culturally sensitive and inclusive. Participants agreed that no single ethical framework can be universally applied, as concepts such as “public good” and acceptable data use differ across contexts. Establishing shared global “red lines” grounded in common human values could provide a foundation, while more flexible “orange lines” allow for adaptation to local norms and realities. This balanced approach would help ensure that digital health and AI systems are not only effective, but also socially acceptable across diverse settings.

Conclusions and future opportunities

Participants agreed that global dialogue on the use of health data must continue. Sustained engagement is essential to build both the momentum and the practical foundations for international solutions, such as a Global Health Record or the broader vision of a Global Health Data Space, building on initiatives like the EHDS. These discussions play a vital role in sharing technical approaches and fostering mutual understanding between countries – enabling the exchange of ideas and learning from diverse national experiences. While approaches differ, many countries are already moving in similar directions, even if they do not explicitly frame their work as “data spaces.”

For example, developments include certification schemes in Japan and Korea; national health data platforms and research infrastructures in Canada, Singapore, and Australia; and new legislative frameworks in Switzerland and Singapore. Several of these initiatives are being designed with future interoperability in mind, including potential alignment with the EHDS.

The group also noted that global progress would benefit from more systematic mapping of these initiatives. This should be done from a wider societal and patient perspective, particularly by the EU and like-minded partners. It would support a more balanced and reciprocal approach to global data governance, and encourage movement towards a more inclusive, co-developed model. Participants expressed a strong interest in continuing collaboration through structured follow-up, organised around the four hackathon domains, which support targeted workstreams and can be effectively considered together.

Looking ahead, participants stressed that a global digital health ecosystem needs practical cross-border services beyond shared concepts. Priorities include global ePrescription services and the exchange of minimum datasets, such as the ISO International Patient Summary. These practical use cases can act as building blocks for larger and more integrated systems, and over time they could support the development of a Global Health Record, building on the EHDS and future involvement of third countries. Delivering this vision will require sustained focus, political will and clear value creation through practical, demonstrable steps.

Global health data collaboration is not short of ideas. The bigger gap is in practical coordination, shared accountability and visible demonstrations of value. The next phase should therefore focus on implementable pilots, measurable public benefit and reciprocal learning between regions, rather than more high-level agreement alone.

Future opportunities

- **Set up a lightweight global exchange and learning platform**
  Create a simple practical mechanism, such as regular virtual roundtables supported by a shared knowledge hub. This could help countries map and exchange health data initiatives, including policy developments, technical approaches and patient engagement practices. It should prioritise usability and continuity over complexity, and aim for quick wins in knowledge sharing.

- **Launch focused, cross-domain working groups with clear outputs**
  Create small, action-focused working groups aligned to the four domains. Each group should have clear outputs, such as guidance notes, pilot proposals or comparative analyses. The groups should stay connected so that work remains aligned across domains, while keeping a strong focus on development.

- **Develop a living repository linked to a phased global roadmap**
  Build a shared and evolving repository of good practice, case studies and evidence of impact. This should feed directly into a practical, step-by-step roadmap towards the vision of a Global Health Data Space. The roadmap should include clear milestones, priority use cases and voluntary commitments from participating countries.

> *To reach a truly global digital healthcare system, however, we need to work much more profoundly and more decisively on real worldwide cross-border eHealth services, like a global ePrescription system or sharing of minimum sets of data (e.g. the ISO International Patient Summary) and progressively bigger components. A global (electronic) health record (GHR) is achievable with focus, concrete steps, value creation and determination.*
>
> \- ***H. Martins (2020)***

Appendix 1 – How did the hackathon work?

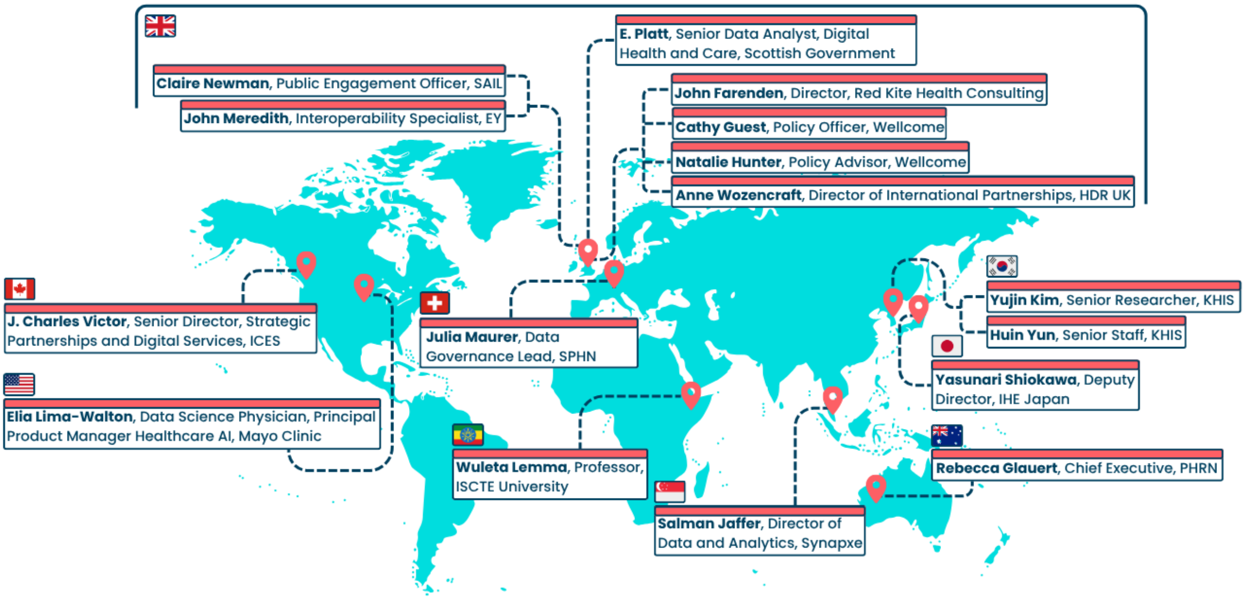
The Global Health Data Hackathon used a structured and collaborative approach. It was designed to move from shared problem identification to co-developed solutions across the main health data domains.

On day one, participants worked in multidisciplinary breakout groups. The groups were designed to include perspectives from different continents. Participants identified and compared country-specific and cross-cutting challenges in policy and governance, care and research use, technical infrastructure and public awareness. These insights were then brought together through plenary discussions and expert input. This helped build a shared understanding of systemic issues.

On day two, the process moved into a "World Café" format. Groups rotated between topics to develop and refine solutions across the four domains. Structured prompts, based on the challenges from day one, supported the discussion. The process also included facilitated synthesis and collective reflection. It ended with the presentation and consolidation of practical, scalable ideas aligned with EHDS priorities and international good practice.

Appendix 2 – Who was in the room?

The hackathon brought together a diverse group of senior experts from across the global health data ecosystem. Participants represented a range of countries and regions, including Australia, Canada, Ethiopia, Japan, Singapore, South Korea, Switzerland, the USA, and multiple UK nations. The group included leaders in data governance, research, public engagement and technical infrastructure. This created a multidisciplinary and international exchange.



These connections were the result of several months of deliberate relationship-building. They drew on existing partnerships and the convening power of Prof. Henrique Martins' global network. This helped bring together trusted collaborators with deep, practical experience of health data systems.

During the hackathon participants were welcomed to bring their experiences from their home country and/or other geographies from which they may have significant knowledge about the health data sharing environment.

Acknowledgements

Wellcome Trust is kindly supporting UPD's engagement with the EHDS, including the shaping of *EHDS Unpacked*: *Global Health Data Hackathon*. We are grateful for their support in convening international stakeholders to explore inclusive, responsible, and innovative approaches to exploring alignment to the EHDS, and implications for non-EU countries. We would also like to thank the international experts who joined us to for the hackathon with such enthusiasm and commitment to collaboration. We look forward to continuing our journey reflecting on national experiences, identifying shared priorities, and nurturing relationships to bring continued value.

About UPD

Understanding Patient Data (UPD) is the UK's trusted independent voice on patient data. We make the use of patient data more visible, understandable and trustworthy, so it can be used well, responsibly and for public benefit. UPD is a hosted organisation of the NHS Alliance in London. UPD's core work is funded by Wellcome, the Medical Research Council, the National Institute for Health and Care Research, NHS England, the Department of Health and Social Care, and the Office for Life Sciences.

About Prof. Dr. Henrique Martins

Prof. Dr. Henrique Martins, MD, PhD, MLaw, FIAHSI, was one of the first CMIOs in Portugal, and during the years at the Ministry of Health he was responsible for setting the agenda for eHealth in Portugal. He was president of SPMS, Portugal's Digital Health Agency for close to 7 years and the former Member States co-chair of the EU eHealth Network, the highest policy body on eHealth in the Union. Between 2020-2024 he was part of the HL7 Europe Foundation Board of Directors. He works as an academic at ISCTE, FCS-UBI in Portugal, and at Korea University Medicine (Visiting professor), teaching and researching in Digital Health, Healthcare Systems and Transformation, Leadership and Management education for Medical Students and Health Professionals. He is engaged in individual consulting projects in Healthcare Transformation and Digital Health, as Senior Consultant in Digital Health and Innovation for the WHO Athens Quality of Care and Patient Safety Office. He was the coordinator of the XpanDH Project from 2023-2024 and is now the coordinator of two large scale EU-funded projects in health interoperability; XiA (Xpanding Interoperability Alliance), and i2X (Intelligent Implementation of the EHR eXchange format).